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H E L P I N G T H O S E W H O H E L P O T H E R S

# On Becoming a Reluctant Caregiver

## Following an Increasingly Common Path

**By Sharon Palmer**

Muriel Lee had endured a 30-year loveless marriage with a verbally abusive husband and had contemplated divorce when the news came that he was suffering from terminal throat cancer.

"When you are not in a good marriage, you face a moral dilemma about what to do. If your husband is unpleasant, do you leave him or stick it out? I made the choice to stay with my husband," says Lee, who chronicled her five-year experience of caring for her difficult husband in *Journeys: The roads traveled by a reluctant caregiver and an ill spouse* (Beaver's Pond Press, 2002).

Lee is not the only one who has been faced with this decision. Few people back out of caregiving for their spouses, sticking to their wedding vows "in sickness and in health." There are several reasons why spouses in poor relationships decide to become caregivers. Many feel a sense of responsibility due to a common history and rearing children together. Others want to spare their children the burden of caregiving. Sometimes the decision is purely a result of financial considerations. And most people find that caregiving is such an intimate relationship that the sick often want someone who has seen them at their worst to be the ones providing the care.

"I think there are more reluctant caregivers than what we have thought. It's a difficult subject to talk about. You ▶

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*Muriel Lee was a reluctant caregiver to her husband, despite a stormy marriage*

> **"I think there are more reluctant caregivers than what we have thought. It's a difficult subject to talk about. You read books about caregivers saying they had a wonderful experience, but not about people who aren't in good marriages."**
>
> ***— Muriel Lee***

**Reluctant Caregiver** *Continued from page 1*

read books about caregivers saying they had a wonderful experience, but not about people who aren't in good marriages," says Lee.

Caregiving is even crossing boundaries in relationships, putting ex-spouses back in touch with each as they reunite to care for each other. There were 2.726 million divorced Americans older than 65 in 2003, compared with 1.718 million in 1994. Even after divorce, ex-spouses may continue to have close personal relationships due to years of friendship, proximity, or family ties.

Hospice workers are getting more used to seeing ex-spouses at the bedside these days. And they report that there are often positive outcomes, such as getting past old wounds or possibly rekindling lost relationships. Karl Decker Hayes of Monroe, Louisiana, was described as a cruel, controlling husband to his wife, Millie. Even though they divorced in 1998, that didn't stop Millie from caring for her ex-husband once he was diagnosed with Alzheimer's disease.

Reluctant caregivers don't stop with spouses and ex-spouses. They can also include children who have had poor relationships with their parents. In *Caregiving: The Spiritual Journey of Love, Loss, and Renewal*, author Beth Witrogen McLeod shares the story of Linda, a daughter who cared for an abusive mother out of duty and ended up ditching years of painful baggage in order to forgive the past.

## Mustering Strength to "Care"

Taking a deep breath and plunging into the role of caregiver for someone who has treated you badly is probably one of the most difficult challenges most people may face in a lifetime. Some psychologists say that it may not even be the best course of action, as anger and resentment may surface. Sometimes it may be better for everyone involved to have someone else act as a caregiver.

As for those who take on the job of reluctant caregiver, many quickly discover that most available support services are designed for caregivers who are in a loving relationship, not for caregivers overwhelmed with a painful past and resentment. Simply put, they may find themselves in a very lonely situation with neither a close relationship with their spouse, nor a circle of others in a similar reluctant caregiving circumstance.

Caregiving is hard enough without adding a difficult relationship to the mix. Research indicates that caregivers who have poor relationships with care receivers are at higher risk for stress and that the degree of caregiver burden may be more intense in a relationship that started out poorly.

In a study at University College in London, researchers noted that when there is poor quality in the relationship between caregiver and the care receiver, the caregiver often experienced both depression and anxiety with little potential for successful intervention.

What's more, according to research presented at the American Psychological Association in Chicago, researchers were able to predict anger and resentment in those caregivers that had poor relationships with care receivers.

"It took a lot of therapy to get me through it and friends who took care of me," reflects Lee on coping with her caregiving experience. She adds that the hospice program was a tremendous source of support. But probably the biggest coping mechanism for Lee was journaling through her pain. "Journaling helped me cope. It helped tremendously. I had 1,500 pages of typewritten pages when it was over," says Lee, who ended up weaving in writings from her husband with her own pages to complete her book.

## TOP 10 TIPS FOR RELUCTANT CAREGIVERS

Finding methods of coping is extremely important for reluctant caregivers. Here are 10 tips from the experts:

1. Take care of yourself first. Don't ignore your own needs.
2. Acknowledge your emotions, even negative ones. Get emotional support through a support group or therapist.
3. Reduce isolation for both you and your care receiver. Get the care receiver out of the house to a weekly support group or adult day care, if possible. Take advantage of that free time for yourself.
4. Develop reasonable expectations for yourself as a caregiver. Don't help too much.
5. Get some respite care into your home. Rely on community, social, volunteer, or family resources for some of the caregiving duties.
6. Get support from other family members or friends who may have a better relationship with the care receiver.
7. Develop healthy releases, such as exercise, healthy eating, or journaling.
8. Find time for yourself every day.
9. Recognize signs of stress and depression, and get help if necessary.
10. Pat yourself on the back. Take pride in what you are doing.

Lee's story has a happy ending. Since her husband's death, she has published a book and found true love. "My husband was verbally abusive. He lived for five years after he was diagnosed and had a large tumor on his neck, so he lost his voice. He knew it was karma that he lost his voice," adds Lee.

For a few last words of advice, Lee suggests, "You absolutely have to lean on your friends. You also must do something good for yourself every day, even if it's a 15-minute bath or to go outside and look at your flower garden." ■

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# Compulsive Hoarding

## Caregiving in a Sea of Clutter: When Nothing is Thrown Out

**By Ursula Furi-Perry**

As if caregiving itself weren't difficult enough to contend with, for many caregivers the personal habits of their loved ones pose an additional problem. When your loved one hoards or collects everything from junk mail to canned food and even animals, it's easy for the situation to get out of control—for loved one and caregiver alike.

"A lot of families have this issue," says Evie Goldberg, licensed clinical social worker for the Genesis Program, an older adult services division of the Los Angeles County Department of Mental Health.

Hoarding among the elderly happens for a variety of reasons: some collect items for sentimental reasons; some may use hoarding in their quest for perfection and genuinely believe their collections to be prudent and practical; others do it to overcome grief and a sense of isolation.

"What we're beginning to see in our treatment of hoarders aged 60 and over is that a lot of times, there have been losses," Goldberg explains. "Some of these people can't manage any longer to take care of themselves or their residences, or they feel isolated," taking comfort in the presence of familiar objects instead.

### Serious Concern, Even Dangerous

While some collections remain manageable, hoarding can prove to be a serious concern—even a safety issue. "Hoarding becomes a problem when people gather more stuff, in plain language, than they can manage," Goldberg says.

Hoarding is often associated with certain mental illnesses, such as obsessive-compulsive disorder, and may connote an even more serious issue. Besides acquiring a multitude of possessions, compulsive hoarders may exhibit symptoms of indecision, such as postponing important and routine decisions alike. They may also take longer than necessary to complete simple tasks, "mulling over" their strategies for long periods before actually beginning the task.

Yet the loved one's own mental, physical and emotional health is only a small component: others outside of the household may also be distressed by hoarders. "This can affect everyone, like the fire department and building and safety (departments)," notes Goldberg.

In terms of public safety, she says the general community can be adversely affected when "newspapers are piled up, food is left rotting in apartments, and numerous repetitive items appear." Besides sanitary considerations, cluttered living spaces can present major fire hazards for the elderly who may have a tough time getting around.

### Watch Out, Caregivers!

For caregivers, some of the simplest tasks can become nightmarish when caring for a loved one amidst "junk" barricades and among a sea of clutter.

*continues on page 7*

## Protecting Your Elderly

# Medication Alert: Mistakes are More Common than You Think

**By Kelly D. Morris**

"I've got some medication for you," the nurse said cheerfully as she handed Kathleen Meyer a little white paper cup of pills and a glass of water.

Kathleen's daughter looked up from her magazine. She glanced at the pills in the cup just as her mother was getting ready to swallow them. "What's that purple one?" she asked. She recognized the other, but not that one.

"That's her antidepressant," the nurse said.

"My mom's not on an antidepressant!" Kathleen's daughter protested.

The nurse checked the clipboard in her hand, then looked at Kathleen's armband. "Why, you're not Kathleen Miller! You're Kathleen Meyer!" she exclaimed.

Luckily, Kathleen's daughter had been paying attention to what medication her mother was given. Kathleen has epilepsy, and this particular antidepressant could have caused her to have seizures.

Surprisingly, this kind of error is not uncommon. A recent study conducted at the University of Toledo found that slightly more than 53% of hospital in-patients were subject to at least one medication error. Nearly 40% of those errors had the potential to be harmful to the patient, researchers say.

The most common error in hospitals is the omission of a regularly-scheduled medication. Other errors include giving the wrong medication or giving the incorrect dose of a medication.

Errors are most likely to happen in a hospital when a patient is already taking a large number of prescription medications at the time of admission. The best way to prevent such mistakes is to bring all prescription bottles with you any time you have to take your loved one to the hospital for check-in or emergency room care.

Medication errors can occur on an outpatient basis, too. Doctors may prescribe the wrong medication or the wrong dose. Pharmacists may fill a prescription incorrectly. Patients may not understand how to take their medication properly or may forget to take their pills on time.

The elderly and disabled are at particularly high risk for medication errors because they are often on many different medications and often see more than one doctor or specialist, who may not know what the others are prescribing. They also may have difficulty reading directions on medication bottles or remembering to take medications.

Medication errors can be dangerous, even fatal, but fortunately there is much that can be done to prevent them. Caregivers can take an active role in helping their loved ones prevent medication errors. The American Pharmacists Association offers the following suggestions:

*When you take your loved one to the hospital or emergency room:*

- Take all medications with you in the original bottles. Take any non-prescription medications or nutritional supplements as well, because these can sometimes interact with prescription medications.
- Staff should always check your loved one's armband before giving any medication or performing any procedures. Make sure they do.
- Always look at your medication before your loved one swallows it.
- If you elderly is given a medication that does not look familiar, ask what it is. Don't be afraid to speak up if you think

## WHAT'S IN A NAME? PLENTY, IF IT'S MEDICINE

The Food and Drug Administration advises pharmacists and patients to be particularly aware of these medications whose names may sound alike or may look similar when handwritten on a prescription.

Here are some examples of easy confusion:

**Ambien** and **Amen**

**Cardene SR** and **Cardizem SR**

**Clonidine** and **Klonopin**

**Cozaar** and **Zocor**

**Feldene** and **Seldane**

**Flutamide** and **Flumadine**

**Norvasc** and **Navane**

**Retrovir** and **Ritonavir**

**Saquinavier** and **Sinequan**

***Remember this:*** If you have trouble reading the doctor's handwriting on a prescription, the pharmacist may have trouble, too. Ask the doctor to write clearly.

Asking the doctor to note the reason a medication is being prescribed will also help prevent errors. For example, Norvasc is used to treat high blood pressure, while Navane is used to treat psychiatric disorders. If the physician writes "Norvasc, 10 mg for hypertension," it will be easy for the pharmacist to know which medication to dispense.

your loved one might be getting the wrong medicine.

*When you take your elderly loved one to an appointment with a doctor:*

- Take all medications with you to the appointment. Be sure to include over-the-counter medications and nutritional supplements, as well.
- Ask what medications are being prescribed and in what dosage. Find out exactly how the medicine should be taken. For instance, if the doctor says it should be taken three times a day, does that mean to take it once every eight hours or that it should be taken at breakfast, lunch and dinner? Make sure you know why the medication is being prescribed. Write it all down.
- When the doctor writes a prescription, ask him or her to include the purpose of the drug on the prescription. This will help prevent confusion if the name of the medicine sounds a lot like another drug.

*When you pick up a prescription at the pharmacy:*

- Read the label on the bottle. If the name of the medication doesn't look familiar to you, ask the pharmacist about it.
- Make sure you understand the directions on the bottle. Ask the pharmacist, if you have any questions.
- If you're picking up a prescription that your loved one has taken before, look to see if the pills look the same as before. If they look different in any way, ask the pharmacist about it.

*At home:*

- Don't give your loved any medication in the dark. Turn on a light so you can see what you're giving them.
- Keep all prescription medications in the original bottles. Many pills look alike, and it is easy to get them mixed up if they are not in labeled containers.
- Dispose of any outdated medication by flushing it down the toilet.

Talk to your loved one's doctor and pharmacist for further information in your specific situation. ■

*Kelly Morris is former social worker and home health and hospice worker whose freelance writing has appeared in a number of health-related journals. She lives in Mansfield, Ohio, and can be reached at multihearts@hotmail.com.*

## 7 Tips for Living Together

# What to Do When Mom Moves In

**By Paula Tchirkow, MSW, LSW, ACSW**

Congratulations! You finally made the leap and invited your elderly parent to live with you. No doubt it was a tough decision.

Keep in mind, however, that with this decision comes some serious thinking and adjustment for both you and your family. It's not unusual for historical parent-child conflicts to emerge—or even erupt!—under the same roof, reviving dysfunctional patterns of behavior including depression, stubbornness and misdirected anger, all of which can come with the tension of role reversal.

Your parent also may be stressed with the new situation. Consequently, their negative personality traits may surface along with the loss of their independence.

To make this living situation comfortable and happy for all, develop livable house rules immediately upon the decision to move in together. Work out kinks from the beginning. Unfortunately, if your parent has dementia or any kind of memory impairment, guidelines may not be helpful.

Here are seven valuable tips for developing livable house rules:

1. **Recognize Your Limits.** Accept what you can do for your elderly parent. Remember you can never totally repay what he/she has done for you. Leave room for your own needs to be met so this can be a successful reunion.
2. **You're the Head of Household.** Make that role clear from the beginning. You can run a democratic household, but you and/or your spouse cast the tie-breaking vote. Make sure your parent does not undermine your authority. You are the parent of your children, and your parent must follow your lead.
3. **Assign Tasks.** To avoid misunderstandings, make a list of rules prior to Day One. Offer your parent certain chores, if this is appropriate, even if they seem menial. They will feel happier if they feel useful and know what is expected of them. Perhaps, they can weed the garden, set the table, or whatever fits your situation.
4. **Protect Privacy.** Everyone should have privacy, including your parent. Let your parent know if any room is off limits and when. If possible, let your parent entertain their friends, just like you entertain yours. Preserving privacy will help both of you to enjoy your time together.
5. **Choose Your Battles.** Nothing is perfect, but determine which battles are worth fighting and which are not. Keep in mind everyone will need to make compromises.
6. **Establish a Complaint Forum.** Allow problems to be aired as soon as possible so frustrations don't rise to a breaking point. A weekly or monthly family meeting to air grievances can be a solution that works for both of you.
7. **Give It Time.** The beginning of any new living arrangement may be turbulent. It may take months before the dust settles. Give yourself time for adjustments to take place.

Finally, realize this situation may not work for either of you. Before you move in together, consider a Plan B—alternative living arrangements—in case living together doesn't work out. You want to avoid becoming physically and mentally exhausted so your relationship is not impaired. Discuss this alternative at the outset so there are no surprises and so both of you can agree on what's best for everyone—before emotions flair. ■

*Paula Tchirkow is a licensed and certified geriatric care manager. She is president of Pittsburgh-based Allegheny Geriatric Consultants and is a member of our online Ask an Expert board. She can be reached at paula@caregivingadvice.com.*

# How I Cope

## A Tough Caregiver Lesson on Long-Term Care Insurance

**By Jacqueline Marcell**

When I suddenly became a fulltime caregiver to my elderly parents, both with health problems and starting to develop Alzheimer's, I had never even heard of long-term care insurance.

After we burned through their life savings and started chipping away at mine, I was advised to apply them for financial assistance through the government's Medicaid system—a program for those at the poverty level. It was quite a long process with mounds of paperwork and numerous investigations, but finally my parents were approved.

I was so happy that financial help would finally be on the way, until I found out that the financial assistance would only pay to put my parents in a nursing home, not even in assisted living, and would provide very little help to keep them in their own home.

Since their levels of care were so different (my mother needed most things done for her), there weren't any facilities that would allow my parents to be together. They'd be across the street from each other in different wings of a facility.

After 55 years of marriage, my parents were adamant about wanting to stay together in their own home, in their own bed, where they could continue to cuddle and kiss, as they so frequently did. And, since my father was so difficult, with terrible temper tantrums and quite a long record of manipulative disruptive behaviors, no one wanted to deal with him anyway!

It was very challenging, but I committed to keeping my parents together in their own home and attending adult day health care five days a week. Then, after four more years of loving each other, they both passed away, just a few months apart. Even though caring for every aspect of my parents' last years was the hardest thing I have ever done, I am proud to say I gave them the best end-of-life I possibly could.

Had I only known to insist that we buy long-term care insurance for them prior to their illnesses, their years of in-home care could have been paid for and I could have saved myself so much heartache, not to mention a small fortune. As one who learned this lesson the hard way, my hope is that other caregivers learn from my mistakes and look into LTC insurance long before you need it—for your loved ones as well as yourself.

Along the way, keep these facts in mind if you wonder whether LTC insurance is worth the cost or effort:

- An estimated 43% of Americans age 65 or older will spend time in a nursing home.
- By 2012, 75% of Americans over age 65 will require long-term care.
- LTC costs are rising at 6% annually, much faster than any recent rate of inflation.

Here are some tips on how to approach the topic of long-term care insurance:

### Three Ways to Pay for LTC

1. Pay for in-home caregivers and assisted living/nursing homes out of pocket. This is expensive and can often deplete a family's life savings.
2. Meet a very specific poverty level and qualify for government assistance through the Medicaid program. Unfortunately, options are limited, only paying for nursing homes that accept Medicaid.
3. Buy a comprehensive long-term care insurance policy. This protects your family's assets from the rising costs of caring for someone who needs full-time care. An employer might even pay the

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tax-deductible premiums. Consider buying it at a younger age, when it is more affordable and accessible. It must be bought before a major chronic illness strikes. This policy pays for care in the patient's home, assisted living, board and care, and in nursing and dementia care facilities. Medicare and regular health insurance does not pay for long-term care. The average living cost for a person who needs long-term care is $40,000–$70,000 annually, depending on where you live, plus the cost to the family caregiver who may have to leave their job.

### 15 Questions to Ask Your Insurance Agent

1. Is the coverage comprehensive, meaning it includes all levels of care: in the home, assisted living, board and care, and nursing and dementia facilities?
2. What is the daily dollar benefit?
3. Is there 5% annually compounded inflation protection?
4. What is the elimination period? This is the length of time between when an illness begins and receiving benefit payments from an insurer. Also known as the "waiting" or "qualifying" period, policyholders must in the interim pay for these services.
5. Is it a lifetime benefit period or a limited time benefit policy?
6. Is there a spousal discount?
7. Can you hire caregivers privately as well as from an agency?
8. Is the home care benefit based on a daily, weekly or monthly maximum, and if the benefit is not used, can it be used in the future?
9. Does it cover home care coordination of services?
10. How many ADL's (Activities of Daily Living) your elderly can no longer perform does it take to trigger a claim?
11. Is there a time limit for filing a claim?
12. Does it cover the cost of adult day care and adult day health care, hospice, and respite programs?
13. Is it a tax-qualified plan? This has implications on your taxes.
14. Is the company highly rated, and have they ever raised premiums?
15. Can you see the company's published annual audit to check their track record for paying claims? ■

**Hoarding** *Continued from page 3*

To make matters worse, some professionals suggest that hoarding among one generation may breed hoarding among the next. "A lot of people we've been seeing had grandparents or parents who had collected, and now they're collecting," Goldberg says.

Even more sobering special considerations arise when a loved one hoards animals. Having large numbers of animals without the ability to properly care for them can cause serious neglect to those pets. Furthermore, sanitary problems may arise, and hoarders of animals may contract diseases which typically spread from animals to people.

Many state departments of public health have taken the issue to heart, and some states have even passed legislation to curb dangerous animal hoarding. On its website, the Hoarding of Animals Research Consortium at Tufts University recommends that family members and caregivers offer specific assistance to loved ones, and that they consult their community's resources for assistance.

### Five Caregiver Tips

Caregivers facing problems with their loved one's compulsive hoarding may benefit from the following five techniques:

- ***Get help from an outsider,*** a professional. "It helps to get people involved out of their homes," says Goldberg. For referrals, consider turning to your local departments of mental health or public health.
- ***Don't force the issue.*** The Obsessive-Compulsive Foundation's hoarding website warns against clinicians suddenly coming into the hoarder's house and taking away his or her possessions; instead, the process should be gradual and flow at the loved one's pace as much as feasible.
- ***Set limits.*** "One thing I think can be helpful is that nothing new comes in unless something in the home goes out," says Goldberg. "That's something that doesn't threaten people and makes sense (to most)."
- ***Acknowledge that your loved one is making a difficult life change.*** Be there for support—whether it's physical support in helping to move out large objects, or emotional support in praising and motivating your loved one through a positive change.
- ***Seek support.*** "People who have this problem, or have family members who (do), are not alone," Goldberg says, "there are people out there who care, and some have started self-help groups." To find a hoarding support group for yourself or your loved one, contact your municipal agencies, local Area Agencies on Aging, or some of the organizations listed below. ■

## RESOURCES

**Los Angeles County Department of Mental Health Hoarding Fact Sheet:**
www.la4seniors.com/hoarding.htm

**The Obsessive-Compulsive Foundation:**
www.ocfoundation.org/, or (203) 401-2070

**Hoarding Mental Health Resource:**
www.anxietyandstress.com/sys-tmpl/hoarding/

**The Hoarding of Animals Research Consortium at Tufts University, Medford, Massachusetts:**
www.tufts.edu/vet/cfa/hoarding/index.html

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## COMING UP IN SEPTEMBER

- **The Coming Crisis in Caregiving:** How will we cope with the shortage of qualified professional caregivers?
- **Caregiver Headaches.** What to do about those horrible headaches you get from the emotional stress and strain or caregiving.
- **Retirement? What's That?** Mapping a strategy to help protect your retirement plans while you face the impact of caregiving on your career and the associated costs on behalf of a loved one.
- **The Medicinal Magic of Music on Our Elderly.** How music comforts, soothes and sometimes sparks new hope of a future for our ailing loved ones.

# Osteoporosis Breakthrough
## May Broadly Increase Seniors' Quality of Life

Millions of older women who suffer from the bone-brittling scourge of osteoporosis may have a solution, thanks to researchers at the University of California, San Francisco, who have discovered that new bone can be formed and maintained by treatment combining a hormone and popular prescription drug.

Implications of the discovery reach beyond osteoporosis, holding promise that stronger bones resulting from the treatment may reduce the number of broken hips and similar brittle-bone injuries in the elderly.

The findings, published in August in the *New England Journal of Medicine*, could boost the quality of life for many seniors and save billions of dollars in medical costs annually in the United States.

"The goal of considerably reversing osteoporosis is realistic," Dr. Eric Orwoll, a professor of medicine at Oregon Health & Science University and one of the leading osteoporosis experts, told Knight-Ridder News Service. Orwoll was not a member of the research team.

The treatment found effective by researchers in their study of 238 women was quite simple—a patient takes a hormone for one year and a popular prescription drug for the next. Participants who took an experimental hormone similar to the FDA-approved Forteo, which builds bone, and followed it with a year of Fosamax, which prevents bone-density loss, saw the bone density in their spines increase an average of 12%.

However, the researchers were stunned by another finding: "If you use this bone-building agent, which is very expensive, for one year and you follow it by nothing, you seem to lose almost all the gains," said Dennis Black, lead author of the study and UCSF professor of epidemiology and biostatistics.

Forteo, also known as a parathyroid hormone, can cost more than $6,000 per year and is prescribed for not more than two years because of indications that it could be carcinogenic with longer term use. By combining Forteo with Fosamax, doctors have a way around the dilemma of how to maintain treatment without the cancer risk of prolonged Forteo use.

Osteoporosis is a major public-health threat affecting 10 million Americans. An additional 18 million—80% of them women—have low bone mass, putting them at risk for developing the disease. ■